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### Role of the UK Biobank Ethics and Governance Council

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of some of the components of outbreak control in stopping the spread of HIV is unproven. Whereas epidemiological surveillance for HIV is probably more advanced than for most other public health problems in low-income and middle-income countries, and has been an important technique in programme planning and implementation, traditional contact tracing has indeed been used less in most democratic countries, and there is no evidence that it has contributed to limiting the spread of HIV. Most countries are now emphasising broad access to HIV testing, counselling, and education, and informing the partners of those found HIV positive. Confidentiality, not secrecy, is a general ethical obligation in medical practice, although specific exceptions are accepted in most societies.

We declare that we have no conflicts of interest.

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## Role of the UK Biobank Ethics and Governance Council

In their Comment (Sept 12, p 861),<sup>1</sup> David Jones and Calum McKellar misunderstand the role of the UK Biobank Ethics and Governance Council (EGC). The EGC is an independent body set up to advise and monitor UK Biobank; it is not a creation of UK Biobank. The EGC does not decide on uses of UK Biobank, as suggested by Jones and McKellar, but rather recommends action as the project develops.

The Council's role is to safeguard participants' interests now and in the future because it is the long-

term nature of the project that brings most challenges. No one can predict which applications might be made, and participants agree to take part on this understanding. The EGC advises UK Biobank on keeping participants informed and will advise on applications as and when they arise.

The UK Biobank Ethics and Governance Framework<sup>2</sup> explicitly states that: "Further consent will be sought for any proposed activities that do not fall within the existing consent." This is not a trivial matter. It depends on what is proposed scientifically, expectations of participants, and social mores at the time of an application. It is the responsibility of the EGC to advise on such circumstances.

The proposition put by Jones and McKellar on somatic cell nuclear transfers was hypothetical and the Council took the view that it is not its role to second guess science or social attitudes at an as-yet-undetermined time.

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- 1 Jones DA, MacKellar C. Consent for biobank tissue in somatic-cell nuclear transfer. *Lancet* 2009; **374**: 861-63.
- 2 UK Biobank. Ethics and governance framework. <http://www.ukbiobank.ac.uk/ethics/egf.php> (accessed Oct 28, 2009).

## Access to pain treatment a luxury for most

Guy Micco and colleagues (Sept 12, p 872)<sup>1</sup> are right to emphasise that, whenever possible, patients near the end of their lives must be free to choose whether their care includes optimum pain relief, or more limited use of opioids with the aim of promoting consciousness and lucidity. However, for most patients worldwide, there is no such choice.

WHO estimates that each year 5.5 million patients with terminal cancer and 1 million with end-stage

HIV/AIDS die without access to adequate pain treatment.<sup>2</sup> According to Sevil Atasoy, President of the International Narcotics Control Board, access to morphine is "virtually non-existent in 150 countries".<sup>3</sup>

When Human Rights Watch spoke to people who had lived with untreated severe pain,<sup>4</sup> they expressed sentiments similar to those of torture survivors: all they wanted was for the pain to stop. Several people told us that they had wanted to commit suicide, had told doctors or friends that they wanted to die, or had prayed for death. We found that barriers to pain treatment access included inadequate education for health professionals, doctors' fear of prescribing opioid medications, inadequate supply and distribution systems, and unnecessarily restrictive regulation—for example, in Ukraine three doctors must sign any opioid prescription. Many of these barriers could be removed through cost-neutral or low-cost reforms.<sup>4</sup>

The desire to die with dignity, according to one's own concept of a "good" death, is universal. Governments should work to ensure access to pain treatment, not as a luxury of the wealthiest nations, but in realisation of a universal human right.

We declare that we have no conflicts of interest.

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- 1 Micco G, Villars P, Smith AK. The Death of Ivan Ilyich and pain relief at the end of life. *Lancet* 2009; **374**: 872-73.
- 2 WHO. Briefing note: access to controlled medications programme, February 2009. [http://www.who.int/medicines/areas/quality\\_safety/ACMP\\_BrNoteGenrl\\_EN\\_Feb09.pdf](http://www.who.int/medicines/areas/quality_safety/ACMP_BrNoteGenrl_EN_Feb09.pdf) (accessed Oct 28, 2009).
- 3 Atasoy S. Statement to the United Nations Economic and Social Council, July 3, 2009. [http://www.incb.org/documents/President\\_statements\\_09/2009\\_ECOSOC\\_Substantive\\_Session\\_published.pdf](http://www.incb.org/documents/President_statements_09/2009_ECOSOC_Substantive_Session_published.pdf) (accessed Oct 29, 2009).
- 4 Human Rights Watch. "Please, do not make us suffer any more...": access to pain treatment as a human right. <http://www.hrw.org/en/reports/2009/03/02/please-do-not-make-us-suffer-any-more> (accessed Oct 28, 2009).



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